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Perceptions of aging and falling ill: a study with elderly persons in palliative care

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Abstract

Objective: to learn the perceptions of elderly persons in palliative care regarding coping with aging and illness. *Method*: an exploratory, descriptive, qualitative study was carried out. The study included 11 elderly persons in palliative care because of oncologic disease. Semi-structured interviews were carried out which were analyzed with the aid of the ALCESTE software. *Results*: two axes were identified from the content analysis. The first, Resist to Survive and Live, has two categories: the first, aging with integrity, portrays the positive perception of the participants regarding the aging process, and coping strategies used to deal with aging and with illness; the other category, resilient development, refers to the life trajectories of the participants and the adversities of the process of development and aging. The second axis, Resist to Die Well, has only one category and refers to the perceptions of the elderly about the stress related to illness. *Conclusion*: the results show that the perceptions of aging and falling ill involved resilience, as the participants focused on what they had gained rather than their losses. In this context, they used resilient coping strategies: spiritual support, cognitive restructuring, and acceptance.

Keywords: Aging. Medical Oncology. Palliative Care. Adaptation, Psychological. Resilience, Psychological.

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INTRODUCTION

Aging is the main risk factor for the development of chronic diseases, including cancer. Neoplasms account for more than 45% of deaths in individuals over 80 years of age, with a tendency towards a gradual increase in mortality rates[1].

Cancer affects the body, mind, social well-being, family relationships, and spirit. Due to this complexity, caring for cancer patients requires an approach that goes beyond biological needs and provides comprehensive therapy, including psychological, social and spiritual components[2].

Psycho-socio-spiritual dimensions rarely occupy a prominent role in the care of elderly persons with life-threatening oncological diseases; treatments focus most of all on increasing survival, and cause suffering. In order to transform this perspective into a profile of relief, the philosophy of palliative care should be applied[3].

The World Health Organization (WHO) defines palliative care as an approach that seeks to provide the best quality of life for patients and families facing life-threatening illnesses through pain relief, the management of pain and other physical problems, including the psychological and spiritual[4].

In old age, one of the causes of psycho-social-spiritual suffering consists of successive losses throughout life that include: awareness of one's own finitude, loss of health and/or physical capacity, loss of quality of emotional relationships, social integration, reduction of quality of life in both a material and cognitive sense[5,6].

All loss generates a reaction known as grief that can be experienced differently by each elderly person depending on their previous characteristics of personality, lifestyle, history of losses and internal and the external resources used to deal with them[7].

From this perspective, one can say that the ability to adapt to the losses resulting from aging and its challenges, including illness, necessarily depends on the resilience developed throughout the life trajectory of each person[8,9].

Resilience is the ability to withstand adversities with flexibility and adaptability. When understood as a process that develops throughout life, resilience is interpreted as a bridge between the processes of coping and development[8,10].

On the other hand, coping consists of responding to a stressor, and in old age past coping experiences serve as a guide to deal with current stressful situations[9]. In this context, the present study aims to answer the following guiding question: How do elderly persons in palliative care cope with aging and becoming ill?

It is hoped that the present study will raise the awareness of health professionals about the importance of listening to the life trajectory of the elderly person in order to understand the coping strategies used in previous situations of loss, in order to help such professionals provide personalized and qualified care. In view of the above, the objective of the present study was to learn the perceptions of elderly people in palliative care about coping with aging and becoming ill.

METHOD

An exploratory, cross-sectional, descriptive, qualitative study was performed. The choice of the qualitative design was due to the fact that it was suitable for research that seeks to understand participants from the meaning they attribute to their experiences, much like the objective of the present study[11].

The data were collected during the months of August and December 2016 in the Medical Clinic and the Center for High Complexity Oncology Care of a university hospital in Brasília, in the Distrito Federal (DF). Eleven elderly persons with cancer undergoing palliative care participated in the study.

The inclusion criteria were: people aged 60 years or over who had a record of palliative care for oncological disease on their medical records. Persons with difficulties in verbalization, expression and organization of ideas were excluded.

The data were collected in three different stages of meetings between the researcher and the participant: 1) an initial talk about the participant's life history in order to encourage rapport between the individual and the researcher, with this step serving as preparation for the subsequent stages. 2) application of a sociodemographic questionnaire to delineate the profile of the individual. 3) interview with a semi-structured script, created after an extensive review of literature in seven databases, which included topics on aging, illness and coping[12].

The interviews were carried out personally by the researcher and were recorded, once the consent of the participants was obtained. They had an average duration of 30 minutes and, after each interview, the researcher wrote down his or her impressions and relevant aspects of the discourse; this continuous record constituted a field diary.

The interviews were carried out until the moment when redundancy was identified in the discourse of the interviewees, which dispensed with the need for new participants in the research and, therefore, characterized the saturation point.

The obtained data were transcribed and submitted to thematic content analysis with the aid of the ALCESTE (*Analyse Lexicale par Contexte d'un Ensemble de Segment de text*) software. This program performs a statistical analysis based on the individualization of the text of each interviewee, which are called Initial Context Units (ICU), when these are processed within the program, Elementary Context Units (ECU) are created, organized into classes interpreted from their meanings [13].

Through quantitative grouping the ALCESTE software generated a dendrogram with two axes and three classes. From the words and verbs with the greatest chi-squared value highlighted in the dendrogram and the field diary, we sought to extract meanings by continuing the analysis of content[14].

Content analysis seeks to describe the content emitted in the communication process through systematic procedures that allow the inference of knowledge [14].

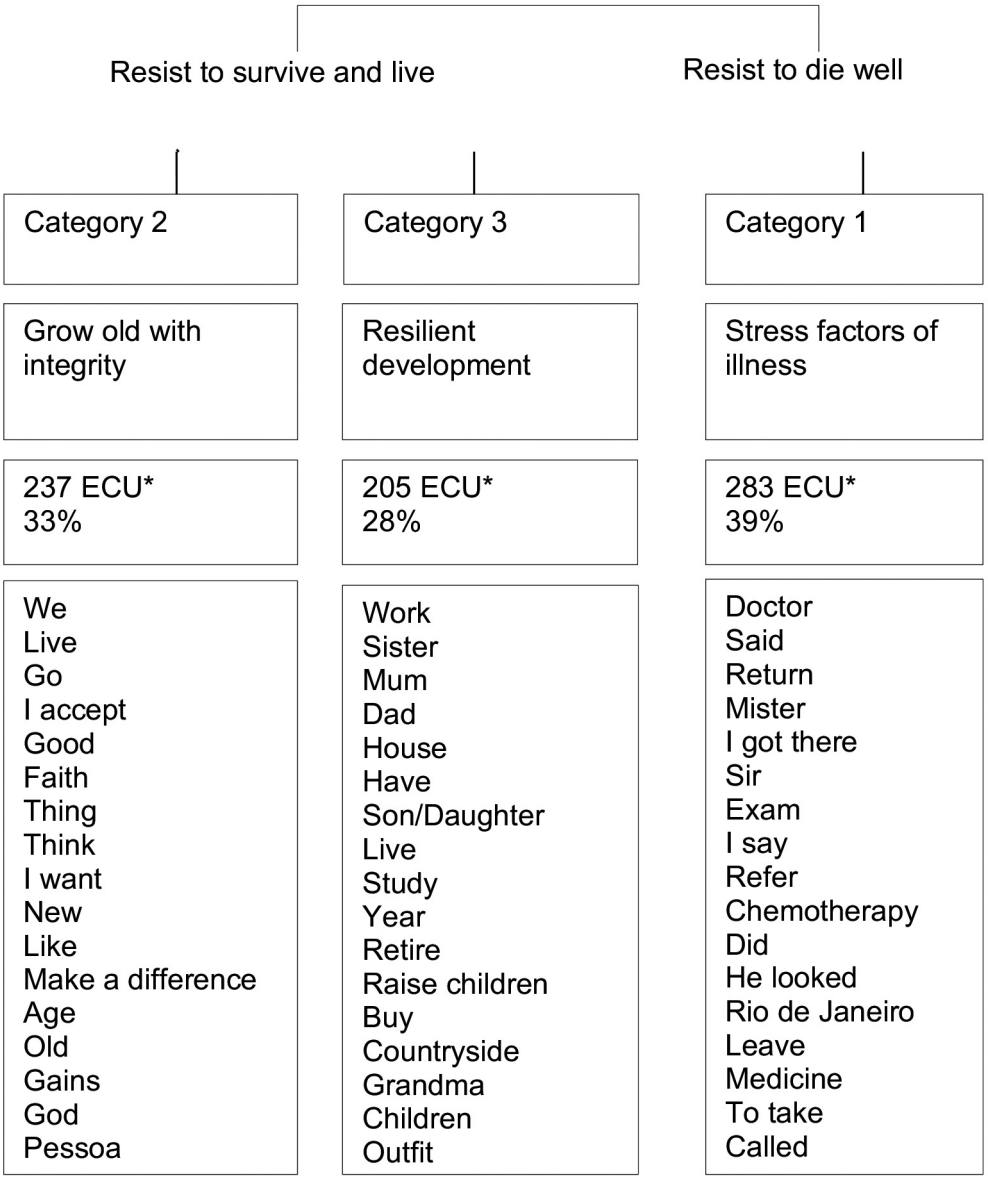
The theoretical references used to support the content analysis were: the classification of coping according to Skinner et al. and the conception of resilience according to Anaut [10,15].

The study was carried out in compliance with National Health Council Resolution nº 466 and was approved by the Research Ethics Committee of the School of Health Sciences of the Universidade de Brasília under approval number 1.667.697. All participants signed the Informed Consent Term and the real names were replaced by aliases.

RESULTS

Eleven elderly persons participated in the study: six men and five women, with a mean age of 68.9 years and a mean of 4.54 years of schooling. Eight elderly persons had been made aware of their diagnosis more than a year previously, indicating some familiarity with the disease. Five needed to leave their city of origin, home and family to seek treatment in the capital, highlighting the difficulties of access to treatment in certain parts in the country.

Content analysis revealed three categories, distributed into two axes (Figure 1). The ALCESTE software identified the words with a greater chi-squared value in each category, as shown in Figure 1.



*ECU: Elementary Content Unit

Figure 1. Dendogram of corpus of interviews organized into two axes and three categories. Brasília, DF, 2016.

DISCUSSION

The first axis, called Resist to Survive and Live, mentions the participants' life trajectories and the strategies used to survive the numerous challenges faced in the aging process. This axis was composed of the categories entitled grow old with integrity and resilient development. The two categories together comprised 61% of the discourse (Figure 1).

The second axis known as Resist to Die Well was formed by a single category, called Stress Factors Of Illness, and explained the difficulties experienced during illness, mainly caused by difficulties in accessing treatment. This category represented 39% of the participants' discourse (Figure 1).

The percentages identified in the first and second axes indicate that during their narratives

the interviewees were more focused on the living process than on the prospect of dying. Similar results were reported in a study conducted in Norway that described the daily life experience of elderly persons with incurable cancer and pointed out the need these people had to maintain a strong connection with life[16].

Resist To Survive And Live

This axis emphasizes that the behavior of the elderly throughout life has remained focused on facing and overcoming adversities rather than avoiding them.

Category 2: Grow Old With Integrity

The excerpts from the prominent words in category 2 point to a positive perception of aging even though the elderly mentioned the losses in their life trajectories. According to Erik Erikson's theory, in old age people may experience feelings of despair when they do not recognize meaning in their life trajectory, or they may experience integrity when they are able to distinguish their losses and achievements and assign a meaning to them[17].

It could be seen that the elderly in this study approached their losses in a positive way and used, according to the classification of Skinner et al., the following coping strategies: 1) cognitive restructuring, 2) spiritual support, and 3) acceptance[15].

1) Cognitive restructuring

Cognitive restructuring is a coping strategy that actively seeks to change the view of a stressful situation so that it is seen in a positive light[15]. It was from this perspective that participants focused primarily on gains, rather than the negative aspects of aging.

> "So it means that aging brought gains for me, I could go out more, I go to my church things, because before I could not, because sometimes I had to take care of the boy." (Lúcia)

> "The things you wanted to have when you were young and you did not have, you have when you get old, as you get older, you're going to have them." (Fernando)

Focusing on the positive aspects, the participants highlighted the material achievements they enjoyed. The reference to freedom as a gain of autonomy and emancipation was also notable. These perceptions value the positive aspects of aging and are corroborated by a study of elderly people attending an Open University of the Third Age. In this study, a balance between gains and losses was identified in both the biological, emotional and social aspects of aging[18].

It was observed that the elderly did not mention the denial of or escape from the problems and restrictions that came as a result of aging They have removed the focus on pain, restrictions and difficulties to live better.

> "With all the tribulation, you know how to live, everything is going well. If you do not know how to live, you won't do well." (Alexandre)

By recognizing, in the aging process, aspects that were beneficial for maintaining well-being despite their tribulations, the cognitive strategy was configured as an important coping tactic.

2) Spiritual Support

Spirituality seeks a connection with God or with a higher power, with that which gives meaning to life and transcends the tangible in search of something greater than the self and which may or may not include religious affiliation[19,20].

In the discourse of the elderly it could be perceived that spiritual support represented a coping strategy that contributed to manage the stress of aging and illness, favoring the attribution of meaning to the process of living.

In the discourse, it was identified that the bases of spiritual support were anchored in faith, in the reading of holy books and the practice of prayer[20].

Faith can attribute meaning to existence, constituting a universal human concern that allows us to follow religious paths towards an organized and value-oriented life[19]. Through faith, the elderly sought an approach to the divine form that governs all.

> "It's faith that takes us away, you're thinking that everything is in God's hands and that it's no use, it's no use worrying, because what's going to be is going to be." (Lúcia)

Religious books were the basis of the values of their lives and arguments for facing the difficulties they experienced.

> "The Bible tells us that when you reach old age, you see, there comes fatigue from the life of others, anguish." (Alexandre)

Prayer represents an important means of approaching the sacred for protection and support in the face of adverse situations as part of the process of getting old and falling ill.

> "Being close to God and praying, and I pray a lot, praying, it seems that it eases things." (Lúcia)

Religious practice based on the reading of holy books, associated with the act of praying, laid the foundation of spiritual support. A study carried out in Croatia found that religious beliefs associated with the act of praying contributed to a greater acceptance of the disease and confronting the psychological adversities that occurred with the diagnosis of cancer[21].

3) Acceptance

The elderly perceived old age as a natural process and as an integral part of life. Although they recognized the evidence of some limitations, they accepted old age in a serene and natural way rather than opposing and trying to modify the situation.

> "I accept old age like this without it bothering me. There's this saying: if you don't want to get old, die at thirty, half, more or less. If you don't want to get old, die young [...] When you accept that this is a natural cycle, when you accept it, there's no loss." (Fernando)

It could be inferred that disease was perceived as part of the aging process. Acceptance is the last step of the stages of death and dying, when the individual has had the time to understand their situation. It seems that the elderly have stripped themselves of their fears and anguish, and are able to manifest feelings of peace and tranquility.

> "Now I'm really recovered. It is good to die happy, better than to die sad, now I am not afraid any more, to die happy instead of dying sad, the worst thing; dying happy is the best thing. Feel safe, happy death you know? It's like this, feel more secure, here I'm safe." (Samuel)

In Samuel's account it was possible to establish a comparison between "happy death" and "sad death"; it was noted that feelings of security, lack of fear and feeling well cared for in the hospital environment made up the expression of "happy death". A similar discourse was evidenced in a study conducted in Australia with 40 patients in a hospice, where participants reported a feeling of relief as they had found a place that could help them at the end of their lives[23].

Category 3: Resilient development

In this category there emerged from the narratives of the elderly a struggle for life that was permeated by numerous challenges: limited opportunities to access education, financial difficulties, the need to work in childhood to supplement family income, poor housing conditions, lack of basic sanitation and the loss of parents and spouses.

Of the 11 participants, only two were able to finish primary education.

> "We didn't have the opportunity to study, my father lived in the countryside, and in the countryside we traveled leagues to get to school, at that time, there were no free schools, it was paid for and only for those who could afford it." (Maria)

Maria's testimony shows the barriers to access to education due to financial difficulties. In a situation of hardship, children had to work to contribute to family income.

> "Everyone had to work to help at home, we were poor, just our father and mother to support so many children, everybody had to work, even at a young age, they had to work, to help." (Lúcia)

The reality described by the participants corroborates the result of a Brazilian study that relates family income to child labor, indicating that this situation still exists today. It is known that when family income is low, the parents have no alternative and choose to make their children work instead of studying. This choice has a significant consequence for the future, as it impacts on professional qualifications, with consequent difficulties for increasing income, thus perpetuating the cycle of poverty[24].

In Brazil, in 2015, 17.6% of children aged from zero to four years of age and 18.0% of children and adolescents aged five to 14 years lived in households whose maximum monthly income per capita was one quarter of the minimum wage[25].

The interviewees mentioned the poor housing conditions and the lack of access to basic sanitation that they experienced during childhood.

> "My life was a struggle! At that time, there in Formosa, there were lots of straw houses, my mother lived at home like that ... it was wattle and daub, I'm not ashamed to say it, it was wattle and daub, real hard ground." (Maria)

However, faced with all the challenges, the loss of the death of parents in childhood and widowhood represented the most difficult episodes to overcome.

> "Another loss was that I did not know my father, my father left my mother in the countryside of Bahia, it was in fifty-two, when I was born they came to Goiás, he and two other brothers of mine, for me, it was a loss too." (Alexandre)

In childhood, the primary needs for affection are satisfied by the parents. A person's sense of security, recognition, self-esteem, and emotional development are influenced by the active presence of the parents. In this perspective, the loss of a parent, when young, produces a void that can generate repercussions, even in situations of adult life, such as building a family and raising their own children[7].

In this same perspective, widowhood burdens old age with the weight of continuous solitude. The individual loses their companion of many years and of a life built for two, leaving a feeling of emptiness[7].

> "Then I lost my second husband, because I am a widow twice. I lost her father, I was nineteen, after a time I got married again, it's been seventeen years since I lost the second." (Regina)

However, despite the innumerable difficulties and losses, the participants reported facing each adversity that arose in their lives with strength and determination; the marks of struggle, rather than evasion, are imprinted on the trajectory of their lives. They were proud of their values and humble origins..

> "I have never stolen, never inherited, all by my own sweat; since childhood, fighting to the end." (Marcelo)

The struggle for survival has given meaning to life; despite adversity, pride in the lived experience and values learned were part of the concept of integrity. The narrative of the elderly confirms that the integrity described by Erikson allows one to be able to experience old age by recognizing their achievements and triumphs[17].

In this context, it can be seen that resilience constructed throughout the live of the individual stood out as a way of dealing with the adversities experienced, and as such, the participants can deal with stress from a positive persepctive[10].

Resistance to die well

This axis relates to the main stressors of illness and the perception of the elderly about their health condition.

Category 1: Stress Factors of Illness

In the narratives of the elderly, it was noted that disease and treatment represent stress factors, notable among which are: the signs and symptoms of the disease, the diagnosis and, above all, the lack of access to treatment.

Cancer consists of a growth in the number of cells that invade tissues and organs, creating masses that alter the initial structure of an organ and that can spread to other regions of the body[26]. The discovery of masses in one's own body was the first sign and stressor perceived by the participants.

> "She said: you have a lump under your tongue, right here, she put her finger on it, it was a hard lump." (Alexandre)

As well as such masses, the participants referred to pain and anorexia as symptoms that made them suspect they had a serious illness.

> "What I am feeling, I'm going to tell you, this pain here never stops." (Eduardo)

> "I lost my appetite, my hunger, I couldn't even bear to look at food, when I got here I weighed 60 kilos." (Samuel)

The health complaints of those interviewed agreed with a study that indicated the prevalent symptoms among those with advance stage cancer: pain (78.4%), anorexia (64.4%) and constipation (63.5%)[27].

Pain is one of the most common symptoms experienced by elderly persons with cancer, and is hard to assess and manage due to its subjective nature. The consequences of poor pain management include: depression, anxiety, substance abuse, cardiovascular problems, delirium, insomnia, functional impairment and a loss of appetite that generally results in weight loss[28].

Anorexia is also part of the process of oncological disease and is associated with an increase in inflammatory activity, with reduced intestinal absorption capacity and a loss of muscle mass in hypercatabolic states, characterized by increased weight loss[28,29].

Additionally, among the elderly it is associated with other factors that contribute to a loss of appetite: social, physical, psychological and medical factors. In this context, close contact with family members can contribute to avoiding the worsening of anorexia[30].

The physical signs in one's body lead to the suspicion of a serious illness which results in a heightened level of stress. Despite such suspicion, bad news about an illness can still have a significant impact on their lives.

Bad news can lead patients to experience anticipatory pain related to all the losses that they have and will have in the future: loss of functionality, of their social role, and possible death. As a result, some people with serious diseases prefer not to know the truth about their diagnosis[31].

Although literature describes hesitation at the moment of diagnosis, the elderly persons in the present study were unanimous in stating that they wanted to have access to the truth and be given complete Information about their health condition.

> "I said: what's the bad news, doctor? You're going round in circles, aren't you? All this chit-chat, I say: I already know what it is, you can open your mouth and tell the truth!" (João)

Despite the negative feelings derived from receiving a diagnosis of cancer, the main stress factor was the difficult access to treatment, which was described as distressing. Some said that the treatment in their own towns was inadequate, and that as a result they had to move to the national capital seeking a firm diagnosis and adequate treatment.

> "I came here because things were a bit of a mess in my life, but the guy said it was diabetes, so I came here to have this treatment. When I got here, the doctor said: I'm going to refer you, and he did, and I had a clinical exam there..." (João)

In addition to the difficulty of starting treatment, the participants also described having to abandon it due to a lack of technical resources:

> "Lots of people have to abandon treatment, don't they? They have go to another state, they say the machine is broken, some say yes, others say no, so you have to leave, but that takes another month, because it was a waste of time going there, to Rio de Janeiro." (Samuel)

The reports of those interviewed validate another study which described the main barriers in cases of oncological disease: the discovery of the disease and the difficulties of access to treatment; including delays in diagnosis, difficulties in access to tests, collateral effects and barriers to carrying out treatment[32].

It is important to point out that the present study has limitations, namely that the research was carried out in a single public oncological care institute, which prevents comparison with other scenarios. Future studies can expand the research context to identify coping strategies in other contexts.

CONCLUSION

The results show that, throughout the life trajectory of the studied group, coping with adversity has forged a capacity to positively manage the stressors identified in their narratives.

Perceptions about the process of aging and illness showed that for these individuals aging was a privilege and, despite its difficulties, they were grateful for life, and so experienced integrity rather than hopelessness.

Nevertheless, illness and access to treatment were perceived as stress-generating events, constituting a source of distress and suffering. In order to cope with the losses and adversities of aging and illness, they used, above all, the coping strategies characteristic of a process of resilience, such as: spiritual support, cognitive restructuring and acceptance.

It is understood that the health team's understanding of coping strategies can add quality to the care provided to such individuals. Therefore, it is suggested that this theme is disseminated among professionals who provide care to the elderly in palliative care, through group discussions and continuous training activities in health institutions.

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